

# House Study Bill 262

HOUSE FILE \_\_\_\_\_  
BY (PROPOSED COMMITTEE ON  
HUMAN RESOURCES BILL BY  
CHAIRPERSON SMITH)

Passed House, Date \_\_\_\_\_ Passed Senate, Date \_\_\_\_\_  
Vote: Ayes \_\_\_\_\_ Nays \_\_\_\_\_ Vote: Ayes \_\_\_\_\_ Nays \_\_\_\_\_  
Approved \_\_\_\_\_

## A BILL FOR

1 An Act creating a hemophilia advisory committee and providing an  
2 effective date.  
3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:  
4 TLSB 2808HC 82  
5 jr/es/88

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1 1 Section 1. NEW SECTION. 135N.1 SHORT TITLE.  
1 2 This chapter shall be known and may be cited as the  
1 3 "Hemophilia Advisory Committee Act".  
1 4 Sec. 2. NEW SECTION. 135N.2 LEGISLATIVE INTENT AND  
1 5 FINDINGS.  
1 6 1. It is the intent of the general assembly to establish  
1 7 an advisory committee to provide recommendations on  
1 8 cost-effective treatment programs that enhance the quality of  
1 9 life of those afflicted with hemophilia and contain the high  
1 10 cost of that treatment.  
1 11 2. The general assembly finds inherited hemophilia and  
1 12 other bleeding and clotting disorders are devastating health  
1 13 conditions that can cause serious financial, social, and  
1 14 emotional hardships for patients and their families.  
1 15 Hemophilia and other bleeding and clotting disorders are  
1 16 incurable, so appropriate lifetime care and treatment are  
1 17 necessities for maintaining optimum health. Advancements in  
1 18 drug therapies are allowing individuals greater latitude in  
1 19 managing their conditions, fostering independence, and  
1 20 minimizing chronic complications. However, the rarity of  
1 21 these disorders coupled with the delicate processes for  
1 22 producing factors and administering anticoagulants makes  
1 23 treating these disorders extremely costly.  
1 24 Sec. 3. NEW SECTION. 135N.3 ESTABLISHMENT AND DUTIES OF  
1 25 HEMOPHILIA ADVISORY COMMITTEE.  
1 26 1. The director of the department of public health shall  
1 27 establish an advisory committee known as the hemophilia  
1 28 advisory committee.  
1 29 2. The committee shall review and make recommendations to  
1 30 the director concerning but not limited to the following:  
1 31 a. Proposed legislative or administrative changes to  
1 32 policies and programs that are integral to the health and  
1 33 wellness of individuals with hemophilia and other bleeding and  
1 34 clotting disorders.  
1 35 b. Standards of care and treatment for persons living with  
2 1 hemophilia and other bleeding and clotting disorders.  
2 2 c. The development of community-based initiatives to  
2 3 increase awareness of care and treatment for persons living  
2 4 with hemophilia and other bleeding and clotting disorders.  
2 5 d. Facilitating communication and cooperation between  
2 6 persons with hemophilia and other bleeding and clotting  
2 7 disorders.  
2 8 Sec. 4. NEW SECTION. 135N.4 MEMBERSHIP.  
2 9 1. The following persons shall serve as nonvoting members  
2 10 of the committee:  
2 11 a. The director of public health or a designee.  
2 12 b. The director of the department of human services or a  
2 13 designee.  
2 14 c. The commissioner of insurance or a designee.  
2 15 2. The following voting members shall be appointed by the  
2 16 director, serving three year terms:  
2 17 a. One member who is a board-certified physician licensed,  
2 18 practicing, and currently treating individuals with hemophilia

2 19 or other bleeding and clotting disorders.  
2 20 b. One member who is a nurse licensed, practicing, and  
2 21 currently treating individuals with hemophilia or other  
2 22 bleeding and clotting disorders.  
2 23 c. One member who is a social worker licensed, practicing,  
2 24 and currently treating individuals with hemophilia or other  
2 25 bleeding and clotting disorders.  
2 26 d. One member who is a representative of a  
2 27 federally-funded hemophilia treatment center.  
2 28 e. One member who is a representative of an organization  
2 29 established under the Iowa insurance code for the purpose of  
2 30 providing health insurance.  
2 31 f. One member who is a representative of a voluntary  
2 32 health organization who currently services the hemophilia and  
2 33 other bleeding and clotting disorders community.  
2 34 g. One member who is a patient, or caregiver of a patient,  
2 35 with hemophilia.  
3 1 h. One member who is a patient, or caregiver of a patient,  
3 2 with a bleeding disorder other than hemophilia.  
3 3 i. One member who is a patient, or caregiver of a patient,  
3 4 with a clotting disorder.  
3 5 3. The committee appointments may be made notwithstanding  
3 6 sections 69.16 and 69.16A.  
3 7 4. If there is a vacancy on the committee, such position  
3 8 shall be filled in the same manner as the original  
3 9 appointment.

3 10 Sec. 5. NEW SECTION. 135N.5 MEETINGS.  
3 11 1. The committee shall meet no less than four times per  
3 12 year and is subject to chapters 20 and 21 relating to open  
3 13 meetings and public records.  
3 14 2. Members of the committee shall receive no compensation,  
3 15 but may be reimbursed for actual expenses incurred in the  
3 16 carrying out of their duties.

3 17 Sec. 6. NEW SECTION. 135N.6 REPORT REQUIRED.  
3 18 The committee shall, by January 15, 2008, and annually  
3 19 thereafter, submit to the governor and the general assembly a  
3 20 report with recommendations for maintaining and improving  
3 21 access to care for individuals with hemophilia and other  
3 22 bleeding and clotting disorders. Subsequent annual reports  
3 23 shall report on the status of implementing the recommendations  
3 24 as proposed by the committee and on any state and national  
3 25 activities with regard to hemophilia and other bleeding and  
3 26 clotting disorders.

3 27 Sec. 7. EFFECTIVE DATE. This Act, being deemed of  
3 28 immediate importance, takes effect upon enactment.

3 29 EXPLANATION

3 30 This bill creates a hemophilia advisory committee within  
3 31 the department of public health. The committee may advise the  
3 32 director of public health on a variety of matters, including  
3 33 proposed legislative or administrative changes relating to  
3 34 hemophilia, standards of care and treatment, the development  
3 35 of community-based initiatives to increase awareness of care  
4 1 and treatment for persons living with hemophilia and other  
4 2 bleeding and clotting disorders, and facilitating linkages for  
4 3 persons with hemophilia and other bleeding and clotting  
4 4 disorders.

4 5 The committee has 12 members, with the director of public  
4 6 health, the director of the department of human services, and  
4 7 the commissioner of insurance, or their designees, serving as  
4 8 nonvoting members. The director of public health will appoint  
4 9 nine voting members representing a variety of stakeholder  
4 10 interests.

4 11 The bill has an immediate effective date.

4 12 LSB 2808HC 82

4 13 jr:nh/es/88